PREFACE

WHAT ARE "RACIAL AND ETHNIC DISPARITIES IN HEALTH"?

"Health disparities are the differences in the incidence, prevalence, mortality,
and burden of diseases and other adverse health conditions that exist
among specific population groups in the United States."

Source: The National Institutes of Health (NIH) Health Disparities Work Group

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What is the *CENTERED* Project?

The *CENTERED Evaluation Guidebook* is the product of a Centers for Disease Control
(CDC) funded special interest project (SIP #25-1999; Cooperative Agreement Number
U48/CCU409664-09) now known as the *CENTERED* Project. *CENTERED* is an
acronym that stands for:

Community-based **E**valuation **N**etworks **T**argeting
Elimination of **R**acial and **E**thnic **D**isparities

The purpose of the project is to develop evaluation support for community-based public
health (CBPH) programs that target elimination of racial and ethnic disparities in health.
Health disparities are inequities in health of one group when compared to another group.

A Story of A Native Hawaiian Community Getting Involved: Empowerment Through Participatory Research Works

Invisibility: Native Hawaiians, as with many small ethnic groups, remain invisible
on the national agenda. Numbering just over 200,000 in the 1990 US Census, Native
Hawaiians have historically been either part of the "Other" group or the "Asian
American/Pacific Islander" group as defined by the U.S. Office of Management and
Budget's (OMB) Directive 15. In 1997, this directive was redefined separating the
categories into: 1) Asian Americans, and 2) Native Hawaiians and Other Pacific
Islanders. This desired change has yet to be fully integrated into the federal health
and funding arenas, resulting in still inadequate data sufficient to fairly describe the
health needs of this indigenous population.

In their own homeland, Native Hawaiians have a mortality rate 41% higher than non-
Hawaiians; a heart disease mortality rate 38% higher than the state population; a
cancer mortality rate 45% higher than the state population; and, a diabetes mortality
rate that is twice that of the other four major ethnic groups combined (Blaisdell, 1996;
Johnson, 1998; Look, 1995). This same pattern of disparities is also found in the
behavioral risk factors and social indicators that are correlated with poor health status.

The need for current and accessible data specific to Native Hawaiians is critical when trying to compete for resources.

While the state of Hawaii collects ethnic-specific data through the CDC-sponsored Behavioral Risk Factor Surveillance System (BRFSS), Native Hawaiian data continues to be aggregated within the Asian American/Pacific Islander group. This practice renders the data "misleading" for use in advocating for health needs specific to Native Hawaiians, which is masked when aggregated with data describing the larger Asian American population. For example, while Hawaii boasts the longest life expectancy in the nation, this is largely due to the longer lifespan of the Asian American women who live in the state. This optimistic life expectancy masks the significantly elevated mortality rates found among Native Hawaiian for heart disease, cancer, and diabetes (see above).

While the health disparities among Native Hawaiian populations made them very attractive to researchers, a major division developed between the researchers and the Native Hawaiian community. Because the Hawaiian community wanted to pursue a participatory research model, but the university researchers did not, the first team of university researchers had to be replaced. This project has since become an example of what can be expected when the community is empowered and it's interests are valued and incorporated into the project.

The Wai`anae Cancer Research Project (WCRP) is one of seven avoidable-mortality research initiatives funded in 1990 by the National Cancer Institute. The original purpose of the project was to test the effectiveness of a community intervention to impact breast and cervical cancer screening practices among Native Hawaiian women. A participatory research strategy was used and defined by the community of Native Hawaiians as, "... research conducted with the full and equal involvement, at all levels and in all stages, of scientists and representatives from the intervention population." The Hawaiian community wanted to share equally in research planning, implementation, evaluation, and results dissemination. They also wanted to share in whatever benefits might result from the project. A major outcome of was a true partnership that utilized the scientific and technical knowledge in the area of research as possessed by the academic researchers, and the equally valuable personal and cultural knowledge possessed by the Native Hawaiian community, thus enabling documentation of the results of a true participatory research effort (Matsunaga et.al., 1996).

The distinguishing features of the WCRP Project included:
1. A community-driven, culturally appropriate intervention based on Hawaiian values and practices;
2. A core group of community members, researchers and health professionals working within a broader community network; and,
3. Tangible community benefits such as:
   - Grant management by the local community health center;
   - Jobs and training for community people involved in the project;

- Improved and new health services based on research findings; and,
- Dissemination of research findings to the community first (Banner et. al. 1995).

The WCRP Project's methodology produced demonstrated successes in:
- Increasing participants' awareness and knowledge about cervical and breast cancer risk factors;
- Increasing the cancer screening rates; and,
- Increasing the confidence of participants in their own ability to obtain health care.

The WCRP Project ended in 1995. In addition to demonstrating the effectiveness of participatory research in developing and conducting a culturally competent program, the project also established a number of long-term products including:
- Culturally appropriate cancer prevention and control education materials;
- Protocols for future research efforts, *"Principles and Guidelines for Participatory Research"* and *"Protocols for the Publication and Dissemination of Data"*;
- Guidelines for assisting other communities interested in establishing similar screening programs;
- Development of an evening cancer screening clinic; and,
- Establishment of a women's health network that currently applies the research intervention to the broader community

Told by JoAnn Umilani Tsark
Member, *CENTERED* Blue Ribbon Panel

The History Of Health Disparities In The United States

Health disparities between whites and African Americans in the United States have persisted for over 400-years (Clayton & Byrd, 2000). The impacts of racism on causing and perpetuating these disparities continue to frustrate communities-of-color. Institutionalized racism (those systematic barriers that block fair access of persons-of-color to goods, services and opportunities) built up over generations has created systematic obstacles to attempts to eliminate inequities in employment, education, power, wealth accumulation, and health. Those who seek to eliminate health disparities must address a range of inequities if gains that may be made in health are to be sustained.

Notwithstanding the long history of neglect of health issues in communities-of-color by mainstream health providers and researchers, these communities have survived. They have relied upon alternative ways of caring for community members and addressing health needs. Because of their inability to use the "white only" clinics, African American

communities in the Southeastern United States responded by establishing the first community clinics; and, even graveyards were segregated to prevent mixing of the races.

In American Indian cultures, medicine people have used stories passed from generation to generation to successfully treat those with illnesses. Just as Asians and others continue to rely on traditional systems using herbs and roots, acupressure, acupuncture, and entirely different models of the human body's functioning to understand health and disease. In many of these cultures, spirituality and the wholeness of the health of the body is emphasized—instead of the health of individual body parts. Ancient cultures often emphasized the interconnectedness of health of the individual and health of the community.

Communities need to fully participate in health disparity elimination program planning and evaluation processes as a natural extension of their continuous efforts to improve the health and well being of their members. One project manager, when commenting on the "alienating" factor of many evaluations observed that, "What's on the chart is not in the heart." Eliminating racial/ethnic disparities must allow each community to speak, act and work from what they know in their hearts is best for their situation, for their community.

In the 1960s, the Black Panther Party (BPP) pioneered free social service programs that now are in the mainstream of American life. The BPP's Sickle Cell Anemia Research Foundation, operated with Oakland's Children's Hospital, was among the nation's first sickle cell testing programs, and inspired the federal government's initial funding of sickle cell research (Source: http://freethepantherlegacy.com/yestandtoday.php).

In 1985, Secretary of the Department of Health and Human Services (DHHS), Margaret Heckler issued a major report describing the disparities in health found among racial and ethnic minorities (Malone & Johnson, 1985). With the release of the Malone-Heckler Report, the scale and chronic nature of health disparities became broadly appreciated.

One follow-up report (Byrd & Clayton, 1991) documented the persistence of health disparities over time and attributed their existence to the almost 400-year-old medical-social culture in the United States that the authors felt, "is heavily laden and burdened by race and class problems compounding continued social and economic deprivation. These factors interactively impact and contribute to the adverse health status and outcomes of African American and poor populations."

In 1995, the American College of Epidemiology adopted a health disparities position statement that included the following summary: "The health of all racial and ethnic groups, especially of their disadvantaged members, is of critical importance for public health. Epidemiologists, individually and collectively, are urged to promote health for all through their research, teaching, practice, consultation, influence on policy, and other activities." (Source: American College of Epidemiology, Minority Affairs Committee; 1995—available at www.ace.org).

In 2000, Byrd and Clayton published a scholarly review of the history of health and health disparities among African Americans and other non-whites that documents the

acceptance of double standards relative to what constitutes "normal" in the United States. This acceptance of dual standards has impeded progress towards equity in health.

Healthy People 2010 set as a national objective the elimination of racial and ethnic health disparities by the year 2010. America's legacy of historical scientific racist processes have left an acceptance by many that African Americans (and others) are not on the same level as whites and therefore substandard health care, health delivery, and subsequent poor health outcomes are acceptable for such populations. The existence of dual standards continues to impede efforts to progress towards equity in health.

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WHY ARE AFRICAN AMERICANS IN SUCH POOR HEALTH?

"Why are African Americans in such poor health? ... Every African American lives with the corrosive residue of a 2000-year legacy of presumed inferiority. It is a legacy so ingrained in our culture that we often fail to see it. But its far-reaching effects are clear enough:

- A race- and class-based dual-tier health care system;
- A resilient health deficit for black Americans that dates from slavery;
- The willing acceptance of starkly different indicators of "normal" health status for blacks and whites; and (perhaps most controversial of all);
- The medical profession's relegation of physicians and nurses of color to an inferior caste.

All these factors have a negative impact on African-Americans' health."

> Kirk A. Johnson, PhD
> Bowdoin College, Brunswick, ME
> *(In a review of: W. Michael Byrd & Linda A. Clayton. <u>An American Health Dilemma: A Medical History of African Americans and the Problem of Race ‒ Beginnings to 1900</u> (2000).*

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While the momentum behind *Healthy People 2010* and health disparities elimination was building prior to September 11, 2001, the events of that date shifted the nation's attention—and resources—to bio-terrorism. National public health priorities changed. However, the need for the national initiative to eliminate health disparities has not gone away, and the target populations clearly remain African Americans, American Indians, Alaskan Natives, Hispanics and Latinos, Asian Americans, and Pacific Islanders.

For that reason, the role of evaluation and documentation of programmatic successes and limitations has never been more important. Credible documentation is needed more than ever to demonstrate the effectiveness of community-based public health programs as they work to eliminate health disparities and other social inequities. It is hoped that the

CENTERED Evaluation Guide will be useful in helping build their ability to obtain essential program funding and other resources through telling their stories, evaluating their work, and demonstrating their successes.

Because there are already many excellent evaluation guides available, the *CENTERED Evaluation Guide* does not attempt to address all aspects of the evaluation process, but rather provides guidance to those existing resources (see Chapter 8). The intent of the *Guide* is to address aspects of the evaluation process felt to be most important for those community-based organizations that are working to eliminate racial and ethnic disparities in health. This includes taking steps to assure that evaluation planning and implementation processes are participatory in nature and effectively empowering in the process those most impacted by health disparities. This also includes consideration of racism as a probable contributor to local health disparities; and, the use of "racial equity indicators" as a method for monitoring efforts to eliminate racial inequities, including health disparities. The intent is for the *Guide* is to complement the excellent evaluation resources already available to community-based organizations.